Quantifying multifaceted needs captured at the point of care. Development of a Disabilities Terminology Set and Disabilities Complexity Scale

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ABBREVIATIONS

DTS	Disabilities Terminology Set
IDD	Intellectual developmental disabilities
SNOMED CT	Systemized Nomenclature of Medicine – Clinical Terms

AIMS To develop a Disabilities Terminology Set and quantify the multifaceted needs of disabled children and their families in a district disability clinic population.
METHOD Data from structured electronic clinic letters of children attending paediatric disability clinics from June 2007 to May 2012 in Sunderland, north-east England collected at the point of clinical care were analysed to determine appropriate terms for consistent recording of each need and issue. Terms were collated to count the number of needs per child.
RESULTS A Systemized Nomenclature of Medicine – Clinical Terms subset of 296 terms was identified and published, and 8392 consultations for 1999 children were reviewed. The required number of clinic appointments correlated strongly with the number of needs identified. Children with intellectual disabilities in addition to cerebral palsy and epilepsy had more than double the number of conditions, technology dependencies, and family-reported issues than those without. Disabled children who subsequently died had the highest burden of needs (p=0.007).
INTERPRETATION Detailed data about needs generated outputs useful for local care pathway development and service planning. Sufficient evidence was provided for successful business cases leading to the appointment of additional paediatric disability consultants. Counting numbers of needs and issues quantifies complexity in a straightforward way. This could underpin needs-based commissioning of services.

Disabled children and young people* ('children' is used hereafter to mean 'children and young people') are among the most vulnerable in our society. In comparison with other children they have significantly higher mortality rates[1,2] and care needs.[3] Consequently, there are increased resource implications both for families and for service provision. There are no robust population data about these children, which leads to low prioritization for funding and service planning.

The UNICEF report, 'The State of the World's Children 2013', estimated that there were 93 million disabled children globally, or one in 20 of those aged 14 years and under.[4] England's Chief Medical Officer's special report published in 2013 estimated there were 0.8 million disabled children aged 0 to 18 years in the UK, or 6% of all children.[3] Both reports called for better data to underpin planning and resource allocation, and for the profile of disabled children to be raised.

From limited existing population data, there is evidence of variation in aspects of care for disabled children globally[4] and in the UK.[1–3,5–11] In order to address the multifaceted needs of disabled children in a local population, these must be accurately identified and described. Data are also required to measure the effectiveness of

*We use the term 'disabled children' deliberately. Generally we prefer 'person-first language' because it is more appropriate to describe people 'with' or who 'have' specified characteristics, such as impairments or specific diagnoses. However, consistent with the International Classification of Functioning, Disability and Health, disability is created as a consequence of interaction between a person and their environment. Disability cannot be considered as intrinsic to the person. Hence, we believe that people are in fact disabled, and not 'people with disabilities'.

interventions and support, leading to a continuous cycle of improvement.

The impetus to develop a terminology set that describes the multifaceted needs of disabled children came from two directions. Firstly, a meeting of paediatricians, parents, terminologists, and key stakeholders at the Department of Health in London in December 2012 and secondly, a project overseen by the UK Academy of Medical Royal Colleges to pilot SNOMED CT coded data collection at the point of clinical care in outpatient settings across specialties.[12] SNOMED CT (Systemised Nomenclature of Medicine – Clinical Terms) was created by the amalgamation of the American Pathology terms of SNOMED Reference Terms and Read Clinical Terms V3.[13] It is an international, standardized vocabulary of terms designed to enable clinicians and any other health or care professional in any setting to code diagnoses, procedures, and many other aspects of care and situation into an electronic patient record. SNOMED CT is the preferred terminology for clinical use in the UK National Health Service. Using such a vocabulary ensures consistency, so data from different settings may be accurately compared.

The primary aim of this study was to develop a Disabilities Terminology Set (DTS) based on a review of the range of needs of children in a district disability clinic population in north-east England. The secondary aims were to use the DTS to analyse the complexity experienced by the children and to quantify the additional impact for children and their families of having intellectual developmental disabilities (IDD) as well as other conditions.

The application of these data to care pathway development and commissioning is discussed.

METHOD

Service description

In Sunderland, north-east England, a specialist paediatric disability service has developed since 2001 based in a district general hospital, serving the local populations of Sunderland, Washington, the Coalfields, and parts of south-east County Durham including Seaham and Murton (approximately 70 350 children, in total, aged 0–19y). Some of these areas are among the most deprived 10% in England. Deprivation, all-cause mortality rates, life expectancy, and the proportion of children in poverty are all significantly worse than average for England.[14,15] The local population is relatively static, with low rates of movement in or out of the area, and is predominantly white British (96%), with slowly increasing numbers of black and ethnic minority people including asylum seekers. The service is 'without walls', providing health care for disabled and potentially disabled children across all settings including the paediatric emergency department, inpatient wards, outpatient clinics, outreach clinics in special schools, and care at home including end of life care. During the study period of June 2007 to May 2012, two paediatric disability consultants and one trainee delivered the Sunderland paediatric disability service.

What this study adds

- A Disabilities Terminology Set was successfully defined and used to quantify needs.
- The outputs are useful for service planning and quality assurance of clinical care.
- The sum of needs can be presented using the Disabilities Complexity Scale.

Person-centred, family-centred data capture

To ensure all relevant issues were captured, families were invited to complete a 'traffic light tool'[16] in the waiting room at disability clinic review appointments. This enabled them to bring issues that mattered most to them to the consultation. The following areas were covered: health conditions that commonly coexist regardless of diagnosis (e.g. constipation, disordered sleep, gastro-oesophageal reflux); functioning across a range of domains (e.g. mobility, personal care, vision, hearing, communication, behavioural issues); and environmental issues, including with family, school, housing, equipment, and access to leisure. This informed the consultation and clinic letter sent to families that was stored in the hospital's electronic patient medical record. Clinic lists from the two consultants (first and second authors) were used to identify children for the study. This resulted in an in-depth review of 8392 electronic clinic letters for 1999 children.

Development of the terminology set

Eighty-three new terms were captured iteratively from the clinic letters to include unique conditions, technology dependencies, and family-reported issues. The terms collected from this review were augmented to 122 disability terms by a national team of disability paediatricians, terminologists from England's Health and Social Care Information Centre, a parent representative from the National Network of Parent Carer Forums, and a therapies representative from the British Academy of Childhood Disability. This group took account of the outputs from the Children and Young People's Health Outcomes Forum[17] and the conceptual framework of the World Health Organization's International Classification of Functioning, Disability, and Health (ICF).[18] This embraces family-reported issues as well as health conditions, body function, and structure. Risk of death before 18 years, discussion about preferred place of death, the existence (or not) of an agreed advance care plan and the actual place of death, where relevant, were recorded.

Separate working groups from general and community paediatrics worked with Health and Social Care Information Centre terminologists to develop their top 117 and 178 terms respectively. The groups then came together to remove duplicates, discuss, and refine where terms were similar or overlapping. This resulted in a final set of 296 terms that captured the multifaceted needs of disabled children in detail. Diagnosis in other children was captured at 'headline' level.[19] Each term was matched to a SNOMED CT concept; this required some modifications and some additions to the UK version of SNOMED CT.[12] An

explanatory glossary[20] including all the terms in the DTS was published. Consequently, comparable data about disabled children can be captured by others using the same DTS, regardless of clinic setting, locality, or specialty of paediatrician.

Statistical methods

All terms were recorded in Microsoft Excel, and analysed using R version 3.1.2 (http://www.r-project.org Bell Laboratories, Lucent Technologies, NJ, USA). The *t*-test was used to compare means between two groups and significance testing of differences between median counts for nonparametric data was done using Wilcoxon's test.

The sum of overall needs was calculated for each child as well as the sum of health conditions (C), technology dependencies (T), family-reported issues (F), and need for round-the-clock care (R).

The needs of children with the most common disabling conditions – autism spectrum disorder, cerebral palsy, epilepsy, and chromosomal/genetic syndromic conditions – were compared. Similarly the needs of children who were born preterm were compared to those who were born at term but required neonatal intensive care. To quantify the additional burden for families when IDD were present (defined as an IQ of <70 measured on formal psychological assessment), children with and without IDD were compared for a range of common disabling conditions. Finally, children who died during the 5-year time window were compared to the other groups.

The review was registered with City Hospitals Sunderland NHS Foundation Trust Clinical Governance department who advised that further ethical permissions were not required. All data analyses were undertaken anonymously.

RESULTS

Terminology set

A set of 296 terms capturing the multifaceted needs of disabled children in detail, and of other children at 'headline' level, were published in a SNOMED CT subset online by the Health and Social Care Information Centre.[19]

Care pathways and performance

Almost one-third (538/1999) of children assessed in the disability clinics were discharged to primary care, because no neurodevelopmental or disabling condition was found, or because there were no medical issues requiring paediatric management. Local pathways allow prompt re-referral if new concerns arise (e.g. from the education-based autism outreach team). This complies with the National Institute for Health and Care Excellence guideline CG128.[21] A further 2% (36/1999) of young people transitioned to adult secondary health care (neurorehabilitation or learning disability teams).

Figure 1a stratifies children by number of needs. Figure 1b shows that the average number of paediatric clinic appointments in the 5-year time window correlates with the number of needs. Pearson's rank correlation gave r=0.97 (df=9, p=7.224e-07) evidencing a positive, linear correlation.

Of the 21 children who died during the review period of 5 years, there was a documented discussion in all cases about the possibility of sudden, unexpected death and a written Emergency Health Care Plan for all but one. The parents (who were separated) of the child without a written plan preferred a verbal plan. Of those who died, 24% did so suddenly and unexpectedly. Of those whose deaths were expected (predictable 24 hours beforehand), 100% achieved their choice of place of death, which for 69% was at home and for 31% was in hospital, where the family were able to receive care and support from the team of doctors and nurses who knew them well.

Profiles of children and impact on their families

Profiles of conditions, technology dependencies, and family-reported issues are compared in Table I for children with a range of common disabling conditions, and also for those born preterm, those who had complications at term requiring neonatal intensive care, and those who died. The mean number of conditions recorded was highest at 15 for those who died compared with the other groups where the means ranged from 4.4 to 9.4. This was statistically significant using the Kruskal–Wallis test (χ^2=17.642, df=6, p=0.007). More detailed statistical analyses (post hoc tests using the Wilcoxon rank sum test, [p=1.57e-05 for those who died and those with ASD]) evidenced the significantly higher number of family-reported issues in the group who died compared with groups with other conditions. The box plot in Figure 2 illustrates the medians and ranges in the frequency of family-reported issues from the data in Table I.

Table II highlights the different profiles for children with common disabling conditions according to the presence or absence of IDD. In each condition IDD was shown to be a contributory factor to the accumulation of needs, and this was statistically significant for all conditions except autism spectrum disorders.

The 699 children with IDD had significantly more needs overall than the 1299 without (mean 5.81, range 1–23 with IDD; mean 2.22, range 0–19 without IDD) and significantly more health conditions (mean 5.41, range 0–18 with IDD; mean 2.40, range 0–12 without IDD), technology dependencies (mean 0.16, range 0–4 with IDD; mean 0.03, range 0–2 without IDD), family-reported issues (mean 0.53, range 0–5 with IDD; mean 0.19; range 0–5 without IDD) and were significantly more likely to need round-the-clock care (mean 0.18, range 0–1 with IDD; mean 0.02, range 0–1 without IDD), with a p value of <0.001 in all cases.

The box plot in Figure 3 shows that family-reported issues were more prevalent in all conditions where IDD was present. This was statistically significant for children with epilepsy (p=0.04).

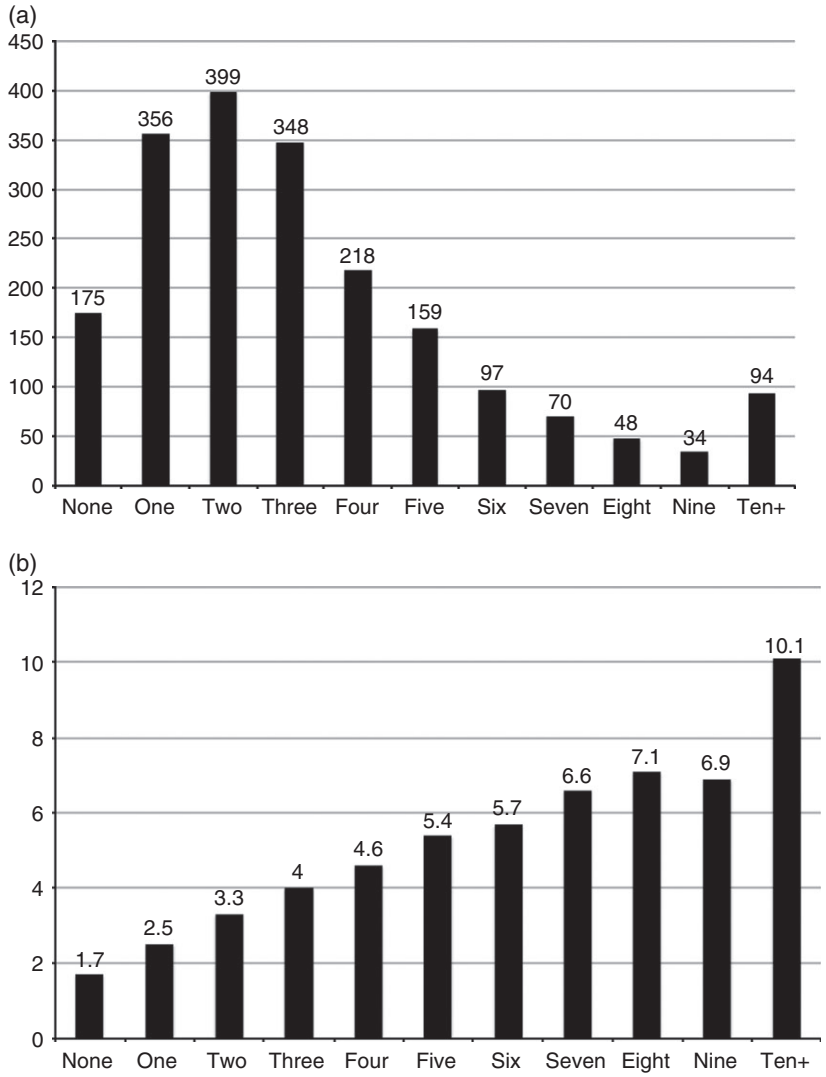

Figure 1: (a) Numbers of children (*y*-axis) stratified by number of conditions, family-reported issues, and technology dependencies per child (*x*-axis). (b) Average number of paediatric disability clinic appointments (*y*-axis) stratified by number of conditions/issues/technology dependencies per child (*x*-axis). (Sunderland Paediatric Disability Clinics, June 2007–May 2012, *n*=1999).

Details of the main conditions, technology dependencies and family-reported issues are shown in Table SI (online supporting information).

DISCUSSION

This study generated unique data that demonstrate the utility and feasibility of profiling needs in a disability clinic population. Analysis confirms the complexity of this group. Whereas a child presenting to a general paediatric clinic might have one or two presenting complaints, children seen in disability clinics typically have many facets to their conditions and situations (Fig. 1).

A particular strength of this study is that it was conducted in a disability-competent, consultant-delivered, population-based local service in a large district with low levels of population movement in or out of the area. All of the clinicians use the same clinic letter format, with lists of active concerns and diagnoses, facilitating consistent data extraction. There are excellent networks with education, social care, voluntary organizations, and a range of clinical specialists regionally, nationally, and internationally. All data were verified by the first author for consistency. This confirmed the reliability of the data extraction. Using a ring-fenced SNOMED CT DTS ensured consistent reporting of issues and thereby mitigated against over-inflation of impact. Working with terminology specialists proved invaluable to ensure absolute clarity of meaning and relatedness for each of the chosen terms, essential for consistency and accurate comparisons between clinicians and settings.

The limitations of the study are that it studied data from a single service; information was gathered from electronic records only, and full paper records were not reviewed; and the sample was incomplete for the identified time

Table I: Percentages with diagnoses, issues, and technology dependencies for children and young people with a range of common disabling conditions and situations (Sunderland Paediatric Disability Clinics, June 2007–May 2012, *n*=1999)

Conditions, technology dependencies, issues	ASD (*n*=579)	CP (*n*=254)	Epilepsy (*n*=181)	Genetic chromo synd (*n*=253)	Preterm (*n*=103)	Term NICU (*n*=67)	Died (*n*=21)
Conditions (mean and range)	4.1 (2–13)	5.8 (1–18)	6.4 (1–18)	4.9 (1–16)	5.7 (1–18)	7.9 (1–18)	12.1 (3–16)
Intellectual disability	35	45	72	69	55	67	95
Autism spectrum disorder		7	19	12	10	10	0
Speech, language, communication disorder	13	28	27	16	20	45	95
Behavioural, emotional disorder	45	18	31.5	23	18	24	10
Attention-deficit–hyperactivity disorder	7	1	4	3	3	1	0
Tic disorder	2	2	2	<1	2	3	0
Developmental coordination disorder	3	0	2	<1	1	3	0
Acquired brain injuries	6	85	20	1	63	69	19
Cerebral palsy	3		29	3	59	66	19
Duchenne muscular dystrophy	<1	0	0	0	0	0	0
Other neuromuscular disorder	<1	0	1	0	0	0	5
Spina bifida	0	0	0	<1	1	0	0
Skeletal dysplasias	0	0	0	<1	0	0	0
Other physical disabilities	<1	<1	1	<1	0	1	0
Epilepsy	6	20		12	13	42	71
Down syndrome	2	0	1	26	1	0	0
Neurofibromatosis type 1	<1	1	0	15	1	0	0
22q11 deletion syndrome	1	1	<1	4	1	0	0
Tuberous sclerosis	<1	0	2	2	0	0	0
Fragile X syndrome	<1	0	0	2	0	0	0
MECP2 disorders	0	0	2	3	0	0	10
Mitochondrial disorders	0	0	2	2	0	0	5
Chromosomal, genetic, syndromes	3	2	9		2	0	38
Progressive intellectual and neurological deterioration	0	0	2	2	0	0	33
Visual impairments	4	21	28	12	20	37	57
Bilateral sensorineural hearing loss	1	8	5	9	19	15	14
Prematurity (<37wks' gestation)	2	25	7	2		0	5
Term neonatal intensive care	1	18	16	0	0		14
Congenital heart disease	2	3	4	18	9	4	10
Developmental brain anomalies	2	8	9	4	3	0	24
Other congenital anomalies	3	5	6	19	12	4	20
Microcephaly (<0.4th centile)	1	15	18	8	10	42	48
Hydrocephalus	1	3	3	<1	6	0	0
Scoliosis	1	19	15	10	14	27	33
Constipation	12	31	29	23	32	40	71
Disordered sleep	24	13	21	17	16	24	33
Gastro-oesophageal reflux disease	1	18	18	10	14	28	62
Drooling	1	14	18	7	11	27	43
Recurrent chest infections	<1	12	18	12	17	28	86
Continence issues	7	15	20	12	8	33	90
Feeding, swallowing issues	5	19	20	13	18	34	86
Ear, nose, throat issues	6	9	8	16	13	12	10
Skin issues	2	4	7	13	3	9	14
Obesity	7	6	4	4	2	3	5
Pain	1	9	9	5	5	13	29
Endocrinopathies	4	4	5	11	7	4	14
Short stature <0.4th centile	1	2	3	3	5	4	10
Iron deficiency anaemia	2	2	2	<1	4	3	10
Technology dependencies (mean and range)	0 (0–1)	0.3 (0–3)	0.2 (0–4)	0.1 (0–4)	0.2 (0–2)	0.5 (0–3)	1.3 (0–4)
Ventriculoperitoneal shunt in place	<1	4	3	<1	5	3	14
Ventilated at home	<1	0	2	1	1	0	10
Tracheostomy	<1	2	1	1	2	0	10
Gastrostomy	<1	9	10	5	8	18	43
Nasogastric tube	0	<1	4	3	0	1	38
Cochlear implant	0	1	0	0	2	1	0
Alternative/Augmentative communication	<1	8	4	1	7	19	14
Family-reported issues (mean and range)	0.3 (0–5)	0.6 (0–5)	0.8 (0–5)	0.4 (0–5)	0.5 (0–4)	0.8 (0–5)	1.5 (0–5)
Child protection plan in place	3	7	9	6	9	7	10
Family issues	11	21	29	19	18	33	43
School issues	8	15	13	10	8	15	24

Table I: Continued

Conditions, technology dependencies, issues	ASD (*n*=579)	CP (*n*=254)	Epilepsy (*n*=181)	Genetic chromo synd (*n*=253)	Preterm (*n*=103)	Term NICU (*n*=67)	Died (*n*=21)
Housing issues	2	6	9	7	9	9	24
Equipment issues	<1	13	12	4	10	16	48
Access to leisure issues	2	3	3	4	1	7	5
Needs round-the-clock care	5	25	31.5	14	19	39	100
Discharged	16	2	3	4	8	3	0
Transitioned to adult secondary health care	1	6	6	4	<1	3	0
Died	0	2	8	7	1	4	
Average number conditions, technology dependencies, and issues per child (mean and range)	4.4 (2–17)	6.8 (1–23)	7.8 (1–24)	5.5 (1–20)	6.5 (1–21)	9.4 (1–23)	15 (5–21)
Average number appointments in 5-year time window per child	4.8	7.0	7.7	4.7	6.2	8.0	12.6

ASD, autism spectrum disorder; CP, cerebral palsy; chromo, chromosomal; synd, syndromic; NICU, neonatal intensive care unit.

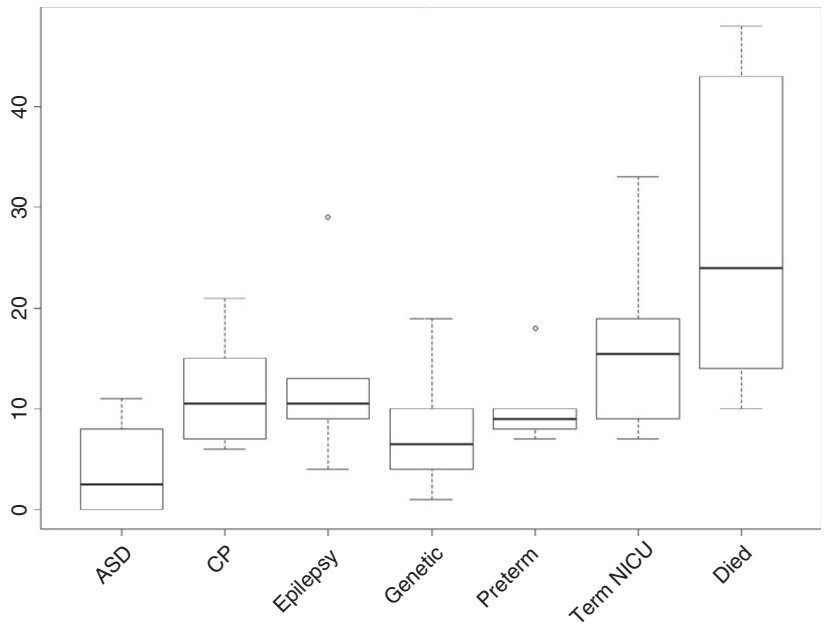

Figure 2: Box plot showing the frequency of family-reported issues for each condition based on the data from Table I. The thick lines represent median values; box edges, lower and upper quartiles; and whiskers, minimum and maximum values (excluding outliers). ASD, autism spectrum disorder; CP, cerebral palsy, Genetic, genetic/chromosomal/syndromic conditions; Preterm, <37 weeks of completed gestation; Term NICU, born at term, required neonatal intensive care.

window, because not all clinic lists could be identified. Only data listed in structured clinic letters could be included, which are likely to under-represent family-reported issues and aspects of symptoms such as pain. This is a well-evidenced determinant of participation and quality of life for disabled children and young people.[22]

Population profiling to inform care pathway development and service design

Profiling subsets of children with specific conditions informs clinical care, by prompting families and clinicians to proactively seek out known associations, identify them early, and manage them in a timely way, to achieve better outcomes. Where there are family-reported issues, the paediatrician can advocate on behalf of the family, for example with supportive letters about housing or timely provision of appropriate equipment.

Defining complexity at population level permits more accurate service planning and resource allocation, essential to more robustly meet needs and reduce inequalities in access to the best outcomes. In our clinic sample, the relationship between the sum of needs per child and the

Table II: Percentages with conditions, issues, and technology dependencies for children and young people with a range of common disabling conditions (Sunderland Paediatric Disability Clinics, June 2007–May 2012, *n*=1999)

Conditions, technology dependencies, family-reported issues	ASD+IDD (*n*=197)	ASD no IDD (*n*=382)	Epilepsy+IDD (*n*=133)	Epilepsy no IDD (*n*=48)	CP+IDD (*n*=114)	CP no IDD (*n*=140)	Genetic, chromo, synd+IDD (*n*=176)	Genetic, chromo, synd no IDD (*n*=77)
Conditions	5.4 (3–13)	3.4 (2–10)	7.6 (2–18)	3.2 (1–11)	8.6 (2–18)	3.6 (1–12)	5.6 (2–16)	3.3 (1–10)
Autism spectrum disorder			19	21	9	5	10	17
Speech, language, communication disorder	13	14	34	6	53	9	18	10
Behavioural, emotional disorder	51	41	35	21	24	13	25	19
Attention-deficit–hyperactivity disorder	8	6	4	2	2	1	2	5
Tic disorder	2	2	1	2	3	1	<1	0
Developmental coordination disorder	2	4	1	2	0	0	<1	0
Acquired brain injuries	4	2	21	17	65	74	1	1
Cerebral palsy	5	2	33	17			3	1
Duchenne muscular dystrophy	0	1	0	0	0	0	0	0
Other neuromuscular disorder	1	0	1	2	0	0	0	0
Spina bifida	0	0	0	0	0	0	<1	0
Skeletal dysplasias	0	0	0	0	0	0	0	1
Other physical disabilities	0	<1	1	0	1	0	0	1
Epilepsy	13	3			39	6	16	4
Down syndrome	4	0	1	0	0	0	38	0
Neurofibromatosis type 1	1	<1	0	0	1	1	3	43
22q11 deletion syndrome	1	1	1	0	2	0	2	9
Tuberous sclerosis	1	0	2	0	0	0	2	1
Fragile X syndrome	1	0	0	0	0	0	2	0
MECP2 disorders	0	0	2	0	0	0	4	0
Mitochondrial disorders	0	0	2	0	0	0	2	1
Chromosomal, genetic syndromes	3	3	10	6	3	1		
Progressive, intellectual, neurological deterioration	0	0	3	0	0	0	3	0
Visual impairments	9	1	35	8	39	7	14	8
Bilateral sensorineural hearing loss	2	1	6	2	12	4	8	12
Prematurity (<37wks' gestation)	3	1	8	4	25	26	3	1
Term neonatal intensive care	3	1	18	8	29	9	0	0
Congenital heart disease	3	1	5	0	4	3	22	10
Developmental brain anomalies	4	1	12	2	11	6	4	5
Other congenital anomalies	4	3	8	0	4	17	19	18
Microcephaly (<0.4th centile)	3	1	23	2	31	2	10	1
Hydrocephalus	1	<1	4	0	4	1	<1	0
Scoliosis	3	1	17	8	32	8	11	9
Constipation	16	9	34	14	46	19	26	14
Disordered sleep	32	20	26	6	25	2	21	9
Gastro-oesophageal reflux disease	3	1	23	4	30	7	14	0
Drooling	2	1	22	4	24	6	8	4
Recurrent chest infections	1	<1	23	2	25	2	17	1
Continence issues	11	5	25	6	26	6	16	3
Feeding, swallowing issues	8	3	26	4	31	9	18	3
Ear, nose, throat issues	6	6	11	0	18	2	17	13
Skin issues	4	2	8	4	5	4	10	19
Obesity	11	5	4	4	7	4	6	1
Pain	2	1	10	6	11	6	4	6
Endocrinopathies	7	2	6	2	4	3	15	3

Table II: Continued

Conditions, technology dependencies, family-reported issues	ASD+IDD (*n*=197)	ASD no IDD (*n*=382)	Epilepsy+IDD (*n*=133)	Epilepsy no IDD (*n*=48)	CP+IDD (*n*=114)	CP no IDD (*n*=140)	Genetic, chromo, synd+IDD (*n*=176)	Genetic, chromo, synd no IDD (*n*=77)
Short stature <0.4th centile	2	1	3	2	4	1	3	4
Iron deficiency anaemia	2	1	1	2	4	1	1	0
Technology dependencies	0 (0–2)	0 (0–1)	0.3 (0–4)	0.1 (0–2)	0.5 (0–3)	0.1 (0–2)	0.2 (0–4)	0.1 (0–2)
Ventriculoperitoneal shunt in place	0	1	4	0	7	2	1	0
Ventilated at home	1	0	2	0	0	0	1	1
Tracheostomy	1	0	1	0	4	0	1	1
Gastrostomy	1	<1	13	2	18	3	7	1
Nasogastric tube	0	0	5	0	1	0	4	1
Cochlear implant	0	0	0	2	1	1	0	0
Alternative/augmentative communication	1	0	4	2	12	5	2	0
Family-reported issues	0.4 (0–4)	0.2 (0–4)	0.9 (0–5)	0.3 (0–5)	0.9 (0–4)	0.4 (0–5)	0.5 (0–5)	0.2 (0–3)
Child protection plan in place	8	1	11	2	9	6	6	5
Family issues	18	8	49	8	33	11	22	14
School issues	11	6	21	6	18	11	8	4
Housing issues	6	1	16	2	7	5	7	0
Equipment issues	0	1	20	4	17	9	6	0
Access to leisure issues	3	1	5	2	5	1	6	0
Needs round-the-clock care	14	0	41	6	45	9	18	4
Discharged	7	21	3	10	<1	4	4	4
Transitioned to adult secondary health care	3	<1	7	2	6	6	5	0
Average number diagnoses, issues, technologies per child	5.9 (3–17)	3.7 (2–11)	9.4 (2–24)	3.6 (1–19)	10.0 (2–23)	4.1 (2–19)	6.3 (2–20)	3.6 (1–11)
Average number appointments in 5-year time window per child	5.5	4.4	8.5	5.5	8.1	6.0	5.2	3.6
Mean difference±intellectual disability	2.02	7.38	7.43	3.06				
95% confidence interval	(−0.59, 4.62)	(4.16, 10.61)	(2.84, 12.02)	(0.27, 5.85)				
Degrees of freedom	116.268	82.673	107.282	120.162				
Effect size r	0.14	0.44	0.29	0.19				
p value	0.128	0.001	0.001	0.032				

ASD, autism spectrum disorder; IDD, intellectual developmental disability; CP, cerebral palsy; chromo, chromosomal; synd, syndromic.

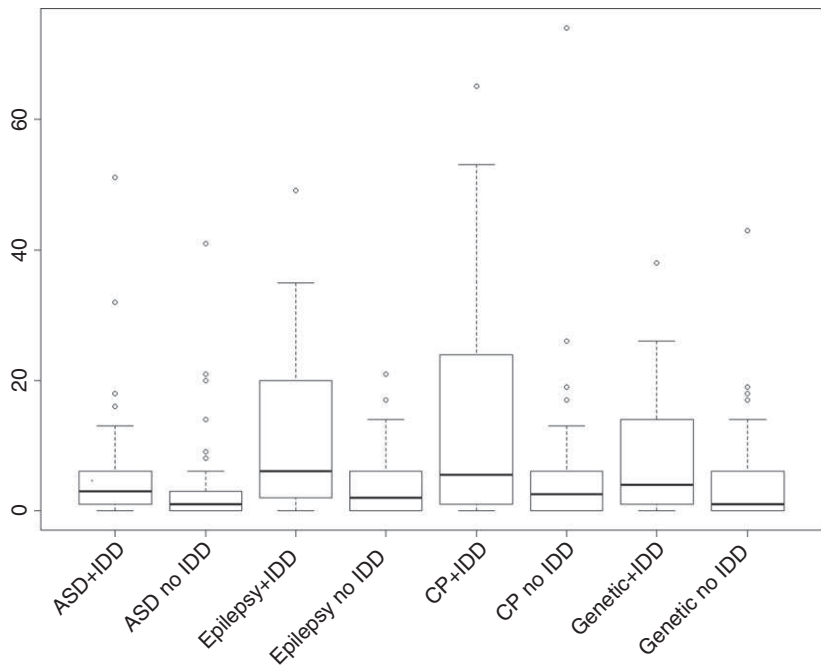

Figure 3: Box plot showing the frequency of family-reported issues for each condition based on the data from Table II, comparing children with and without IDD. The thick lines represent median values; box edges, lower and upper quartiles; and whiskers, minimum and maximum values (excluding outliers). ASD, autism spectrum disorders; CP, cerebral palsy; IDD, intellectual developmental disabilities; Genetic, genetic/chromosomal/syndromic conditions.

number of paediatric consultations attended was virtually linear (Fig. 1), evidencing how individual complexity mapped to service use.

Tables I and II provided data to answer the questions, 'How many children do you see?' and, 'What clinical and other issues do they and their families face?' These data informed the creation of sufficient capacity in the joint postural management clinics (disability paediatrician, orthopaedic surgeon, and physiotherapist) and expansion of the specialist speech and language therapy service to meet the needs of those referred on the autism assessment pathway. Successful business cases led to the appointment of additional disability consultants. All these steps resulted in better provision for the multifaceted needs of these patients. Redesign of the equipment pathway for disabled children is ongoing across agencies, informed by the finding that almost half of families whose children died told us that their equipment arrived too late, did not fit, or was broken (Table I, column 8).

The National Institute for Health and Care Excellence (NICE) in the UK has published guidance on the management of epilepsies in children.[23] However, this focuses very much on the management of the epilepsy itself. For children with epilepsy plus IDD, all of the many facets of conditions and issues need to be correctly identified and managed if the best possible outcomes are to be achieved. Service design needs to be informed by this knowledge, ensuring that the competences of those delivering health care match the needs profiles of the children, including through transition to care in adulthood. In Sunderland, children with epilepsy plus IDD are managed by disability paediatricians with expertise in epilepsy, networking with regional and national experts as required, to ensure that the complex, multifaceted needs of this group are appropriately identified and managed.

From data collection to outcome measurement

The next step after data collection is to record outcomes. Profiling could be used as an additional tool for holistic neonatal outcome monitoring and measurement, as illustrated by the different profiles arising for children born preterm compared to those requiring intensive care at term (Table I, columns 6 and 7). Impact on such profiles in large populations of specific interventions such as therapeutic hypothermia or different ventilation and drug modalities could lead to greater understanding of the outcomes.

The profile of children who died (Table I, column 8) evidences the special complexity of this group. They need particularly intensive support and care to optimize their comfort and well-being in life and dignity in death. Discussions with families about the possibility of death and dying are vital if families are to be involved in decision-making about end of life care.[24] Local population data could be useful for quality assurance of the documentation of such discussions and of the outcomes achieved in terms of place of death.

More complex analyses may include the proportion of children with cerebral palsy who have their condition

described in detail, have access to imaging, or have dislocated hips; the proportion of children with IDD in whom an aetiological diagnosis has been made; and the proportion where family-reported issues have been adequately addressed.

Representing the multifaceted needs of individual disabled children and the impact on their families: the Disabilities Complexity Scale

The complexity scale used in some paediatric neurorehabilitation services, a modification of the Rehabilitation Complexity Scale,[25] although useful, relies on counting the number of professionals in a person's multidisciplinary team. This may not always accurately reflect assessed needs in times of austerity, when multidisciplinary teams are being reduced in many areas.[26] Furthermore, it does not make sense to define the need by the resources that have been allocated, when part of the purpose is to define the resources that are needed.

The sum of needs from a ring-fenced DTS is a better proxy for complexity, especially if the overall score is subdivided to reflect the number of conditions (C), technology dependencies (T), family-reported issues (F), and requirement (or not) for round-the-clock care (R) to give greater detail (see Tables I and II). Thus a child with bilateral dystonic cerebral palsy, scoliosis, feeding and swallowing issues, continence issues, epilepsy, drooling, recurrent chest infections, constipation, disordered sleep, who required neonatal intensive care because of complications at term (10 conditions); gastrostomy and ventriculoperitoneal shunt in place (two technology dependencies); family, housing, and equipment issues (three family-reported issues); and a requirement for round-the-clock care could be represented thus: C10, T2, F3, R1.

IDD is a marker of complexity, as illustrated by the profiles of children with a range of conditions with and without IDD (Table II and Fig. 3). All children with IDD had greater complexity but the average number of needs per child was more than double in those with epilepsy and cerebral palsy. Defining and recording the complexity of an individual child's needs at a point in time allows changes in complexity over time to be documented in a consistent way. One aspect may improve with time, for example 'constipation' may change from an 'active concern' to 'quiet on treatment', while another aspect may become symptomatic, for example epilepsy or pain.

It is necessary to test whether the DTS can be used by a range of clinicians in different settings. It is also important to ascertain whether accuracy of data capture and recording in clinic letters improves with feedback from collated data outputs and ultimately whether clinical care can improve, driven by the prompts of the data capture process.

CONCLUSIONS

This study achieved the aim of quantifying the multifaceted needs of disabled children and underpinned the development of a DTS using SNOMED CT. The potential utility of prospective data capture at the point of clinical care using an agreed set of terminologies is demonstrated.

Complexity – easily quantified using the Disabilities Complexity Scale by adding up the number of conditions (C), technology dependencies (T), family-reported issues (F), and requirement (or not) for round-the-clock care (R) – can be presented in a way that quickly conveys important information for individual care and service planning. The construct validity of the Disabilities Complexity Scale has been evidenced by various analyses.

Profiling the multifaceted needs of disabled children may prompt more proactive care, earlier identification of known associated conditions and issues, and more timely interventions and advocacy for families, with a mechanism in place to monitor and report outcomes and underpin more relevant service and care pathway design.

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SUPPORTING INFORMATION

The following additional material may be found online:

Table SI: Headline conditions, issues, and technology dependencies (Sunderland Paediatric Disability Clinics, June 2007–May 2012, *n*=1999).

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